



ILMI

INDEPENDENT LIVING
MOVEMENT IRELAND

Achieving a right to personal assistance in Ireland



Prepared by:

Bearnairdín Nic Aogáin, Rory Knight, Mary Melvin, Teopista Nannyanzi, Clíona de Bhailís and Professor Eilionóir Flynn

**JANUARY
2019**

Table of Contents

Foreword from ILMI.....	5
Foreword from CDLP	6
About this document.....	7
About the Centre for Disability Law and Policy	7
Key definitions	8
Policy Background	9
Option One: Stand-Alone Legislation on Personal Assistance	12
Background and Context	12
International Case Study: Sweden	13
Background.....	13
Eligibility.....	14
Assessment	15
Hours	16
Funding.....	16
Flexibility.....	17
Development	18
Arguments For	18
Arguments Against.....	19
Option Two: A Comprehensive Right to Community Care and Support.....	21
Background	21
International Case Study: England.....	21
Eligibility.....	21
Assessment	22
Arguments For	23
Arguments Against.....	24
Option Three: Legislation for Personalised Budgets	25
Background	25
International Case Study: England.....	26
Arguments For	28
Arguments Against.....	29
Accessibility	30
Lack of underpinning legislation	31

Option Four: Commencement of the Disability Act 2005	32
Background	32
International Case Study: France	32
Arguments For	35
Arguments Against.....	35
Summary and Recommendations.....	37
Option One: Stand-Alone Legislation on Personal Assistance.....	37
Option Two: A Comprehensive Right to Community Care and Support	37
Option Three: Legislation for Personalised Budgets	38
Option Four: Commencement of Disability Act 2005	39
Overall Recommendation	40

Foreword from ILMI

As chair of Independent Living Movement Ireland (ILMI), I would like to thank the Centre for Disability Law and Policy at NUI Galway for developing this report exploring the options to recognising the right to personal assistance for disabled people in Irish law.

Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. Independent living is about choosing what aspects of social, economic and political life people want to participate in. Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams. For many disabled people, Independent Living can best be achieved by the employment of Personal Assistants to provide supports where needed.

Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals. We believe that a right to a personal assistance service for disabled people is fundamental to achieving that vision.

I would like to thank Bearnairdín Nic Aogáin, Rory Knight, Mary Melvin, Teopista Nannyanzi, Clíona de Bhailís and Professor Eilionóir Flynn for all their work in developing this report.

Our work as a Disabled Person's Organisation (DPO) is to use the information within to build political alliances and continue our campaign for a right to personal assistance. With this excellent report we have the evidence to show how this can best be achieved.

Shelly Gaynor

Chair

Independent Living Movement Ireland

Foreword from CDLP

The Centre for Disability Law and Policy at NUI Galway is delighted to have collaborated with Independent Living Movement Ireland (ILMI) on this important report on options for recognising the right to personal assistance in Irish law. We are dedicated to producing research that drives change, and always seek to collaborate in our work with disabled people's organisations, in keeping with the principle of 'nothing about us without us.' This project with ILMI has been completed by students and staff of the Disability Legal Information Clinic, including Masters and PhD students at the Centre for Disability Law and Policy. The research team was international and drawn from different disciplinary backgrounds, including law, social care and architecture, and included both disabled and non-disabled researchers.

A key objective for the Centre's work is to equip grassroots advocates with evidence-based arguments for change – and this collaboration with ILMI demonstrates how that can best be achieved. This report outlines a number of options for legal recognition of personal assistance as an entitlement of disabled people. Such recognition is a key way in which Ireland can fulfil its obligations under the UN Convention on the Rights of Persons with Disabilities, ratified last year. We hope that this research will prove instrumental in the development of future legislation on personal assistance and look forward to continuing our collaboration with ILMI and other disabled people's organisations to continue to produce research that drives change.

Professor Eilíonóir Flynn

Director, Centre for Disability Law and Policy
National University of Ireland Galway

About this document

This memo has been prepared for Independent Living Movement Ireland (ILMI) in response to their query regarding developing a right to personal assistance in Irish law and policy. It explores four key ways to achieve this objective:

1. The introduction of stand-alone legislation on personal assistance,
2. the introduction of a comprehensive right to community care and support,
3. the introduction of legislation on personalised budgets, or
4. complete commencement of the Disability Act 2005.

It has been prepared by students of the LL.M (Masters in Law) in International and Comparative Disability Law and Policy based at the Centre for Disability Law and Policy in partial fulfilment of a module entitled 'International Disability Human Rights Clinic' and under the Disability Legal Information Clinic. It does not constitute legal advice.

About the Centre for Disability Law and Policy

The **Centre for Disability Law and Policy** (CDLP) at the National University of Ireland Galway was formally established in 2008. The CDLP's work is dedicated to producing research that informs national and international disability law reform, guided by the principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The **LL.M in International and Comparative Disability Law and Policy** is unique in the world as an innovative and internationally focused LLM dealing with the process of law reform in the field of disability. More information about the Centre's work and the LL.M can be found at <http://www.nuigalway.ie/cdlp/index.html>

The **Disability Legal Information Clinic** was launched in 2011. The clinic's main goal is to provide an information service on legal issues related to disability. The clinic also aims to provide a research resource for practitioners and organisations on aspects of disability law.

This research uses a system called **academic referencing**. This lets readers know where to find more information about certain ideas used to make the case for personal assistance. Each time a new idea comes up, a number will appear above the text like 'this¹'. To find out more about the idea you can check the number at the bottom of the page to see where the information originally comes from.

Key definitions

For the purposes of this memo the terms below are defined as follows:

Community Care

The term community care encompasses a broad range of support services (particularly health and social care services) that the State has a duty to provide to its people particularly older people and disabled people. The purpose of these services is to ensure that individuals can remain living in their own homes in the community.

Home Support Service

The Health Service Executive (HSE) Home Support Service (formerly called the Home Help Service or Home Care Package Scheme)¹ provides older people with support with a range of everyday tasks including, dressing, bathing and getting in and out of bed with the aim of allowing older people to remain in their own homes for as long as possible and to support informal carers.

Disabled people

This memo interprets disabled people in line with the UN Convention on the Rights of Disabilities (CRPD) to include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Personal Assistance

Personal assistance is the necessary assistance required by a disabled person to ensure that he or she can participate as a full and equal member of society.² This assistance is directed by the individual to ensure choice and control and it can be adapted to suit various circumstances both within and outside the home. It can include support with personal care, help with household tasks and administration duties, facilitating attendance at work or college, as well as enabling social activities and participation in community life.

¹ Health Service Executive, 'Home Support Service for Older People' <<https://www.hse.ie/eng/home-support-services>> accessed 14 January 2019.

² Center for Independent Living, 'Center for Independent Living Leader Forum Consultation Report: Personal Assistance Services.' (2016) <<https://ilmi.ie/wp-content/uploads/2018/07/Personal-Assistance-Report-2016-.pdf>> accessed 14 January 2019

Personal Budget

A personal budget, also known as a direct payment in the English context, is a 'sum of money given to a person with a disability by a state authority to arrange and meet their care needs instead of having them met directly by the state'.³

Policy Background

In March 2018 Ireland formally ratified the UN Convention on the Rights of Persons with Disabilities (CRPD).⁴ Under Article 19 of the CRPD disabled people have the right to live in the community and have access to a range of in-home and other supports, including personal assistance, to support this. In preparation for ratification and based on a commitment to a national reform of disability service provision and a broader commitment to a right to live in one's own home or in the community there are a number of key government policy documents and objectives which impact the delivery of personal assistance services in Ireland.

The Transforming Lives Programme was established to implement the recommendations in the Value for Money (VFM) and Policy Review of Disability Services in Ireland⁵ which encompasses the 'Time to Move on from Congregated Settings: A Strategy for Community Inclusion' report⁶, 'New Directions'⁷ and Progressing Disability Services for Children and Young People⁸.

³ Janet Carter and Gavin Davidson, 'The Transition To Personal Budgets For People With Disabilities: A Review Of Practice In Specified Jurisdictions' (2012) <<http://nda.ie/nda-files/The-Transition-to-Personal-Budgets-For-People-with-Disabilities-A-Review-of-Practice-in-Specified-Jurisdictions-2012-Word-Format.doc>> accessed 1 December 2018

⁴ United Nations, Convention on the Rights of Persons with Disabilities, Ireland: Ratification (March 2018) <<https://treaties.un.org/doc/Publication/CN/2018/CN.148.2018-Eng.pdf>> accessed 14 January 2019.

⁵ Department of Health, Value for Money (VFM) and Policy Review of Disability Services in Ireland (July 2012) Available at <https://health.gov.ie/wpcontent/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf> accessed 11 January 2019

⁶ Health Service Executive, 'Time to Move on from Congregated Settings: A Strategy for Community Inclusion', Report of the Working Group on Congregated Settings (June 2011) Available at <<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf>> accessed 10 January 2019

⁷ Health Service Executive, 'New Directions Personal Support Services for Adults with Disabilities' (February 2012) <<https://www.hse.ie/eng/services/list/4/disability/newdirections/>> accessed 11 January 2019

⁸ Health Service Executive, Progressing Disability Services for Children and Young People, <<https://www.hse.ie/progressingdisabilityservices/>> accessed 5 February 2019

The VFM review confirmed that personal assistance services were almost exclusively accessed by people with physical and sensory disabilities with a focus on providing these services in the community while others attended group day services.⁹ The public consultation for the review highlighted a need to extend this service to people with intellectual and other disabilities¹⁰ and based on this and other considerations the review recommended that the HSE adopted a person-centred model based on individualised and community based supports for all disabled people on an incremental basis.¹¹

To reflect this and since the publication of the ‘Time to Move on from Congregated Settings: A Strategy for Community Inclusion’ in 2011 there has been an increased focus on moving disabled adults out of congregated settings, defined in the report as ‘settings in which ten or more individuals were living’¹², to community based living. A key component of achieving this goal is providing support to the individuals to live independently in the community. Personal Assistance is one such support. The report outlines that individuals currently living in congregated settings should be moved into community based settings where they will access community, public health and other social support services to enable them to live independently and integrate into the local community. As of June 2018, the Minister for State with Special Responsibility for Disability, Finian McGrath, confirmed that “at the beginning of 2018 there were 2,370 residents remaining in a congregated setting” a decrease from 4,000 people when the process began. He also commented that 170 individuals were projected to move out of such settings in 2018 and 144 people had moved in 2017.¹³

The Health Service Executive has also committed to modernising day services or personal support services for disabled adults. Following a report published in 2012 ‘New Directions’ aims to support adults with disabilities to be ‘be active, independent

⁹ Department of Health, Value for Money (VFM) and Policy Review of Disability Services in Ireland (July 2012)
<https://health.gov.ie/wpcontent/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf>
accessed 11 January 2019

¹⁰ *ibid* 173

¹¹ *ibid* 174

¹² Health Service Executive, ‘Time to Move on from Congregated Settings: A Strategy for Community Inclusion’, Report of the Working Group on Congregated Settings (June 2011) Available at
<<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf>> (accessed 10 Jan 2019).

¹³ Dáil deb 27 June 2018, vol 970, col 188.

members of their community and society’¹⁴, and ‘have influence over the decisions which affect their lives’¹⁵ by providing a range of person centred supports including personal assistance.¹⁶ According to data collected by the Health Research Board 27,902 people with intellectual disabilities availed of at least one day programme in 2017 while 185 required new day programmes.¹⁷ Data on people with physical and sensory disabilities showed that 1,520 people used personal assistance and other support services while 323 people required such services.¹⁸

One of the more recent policy initiatives in this area is the Task Force on Personalised Budgets. Established in 2016 the Task Force published a report in 2018 recommending the trial of three demonstration models for the implementation of personalised budgets in Ireland before a national roll out.¹⁹ The report outlines the model to be adopted from assessment of need to planning and review and governance. It also confirms that personalised budgets will be optional and that some individuals may wish to remain within the traditional service allocation model.²⁰ The Department of Health, National Disability Authority (NDA) and the HSE are currently designing the demonstration models.²¹

¹⁴ Health Service Executive, ‘New Directions Personal Support Services for Adults with Disabilities’ (February 2012) <<https://www.hse.ie/eng/services/list/4/disability/newdirections/>> accessed 11 January 2019

¹⁵ *ibid* 13

¹⁶ *ibid* 89

¹⁷ Sarah Hourigan, Sarah Fanagan and Caraíosa Kelly, Annual Report of the National Intellectual Disability Database Committee 2017: Main Findings (2018) Health Research Board: HRB Statistics Series 37, 12. Available at <https://www.hrb.ie/fileadmin/2.Plugin_related_files/Publications/2018_pubs/Disability/NIDD/NIDD_Annual_Report_2017.pdf> (accessed 14 Jan. 2019).

¹⁸ Anne Doyle and Anne Marie Carew, Annual Report of the National Physical and Sensory Disability Database Committee 2017: Main Findings (Health Research Board: HRB Statistics Series 36 2018) <https://www.hrb.ie/fileadmin/2.Plugin_related_files/Publications/2018_pubs/Disability/NPSDD/NPSDD_Annual_Report_2017.pdf> accessed 14 January 2019

¹⁹ Department of Health, Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets (June 2018) 16 <<https://health.gov.ie/wp-content/uploads/2018/07/Task-Force-Report.pdf>> accessed 14 January 2019

²⁰ *ibid* 12

²¹ Dáil deb 21 November 2018, Unrevised, col 181.

Option One: Stand-Alone Legislation on Personal Assistance

Background and Context

Currently there is no legal right to personal assistance in Ireland. Those in need of this support often find the application process problematic, as there is no standardised procedure²² and those in receipt of this support do not have any security regarding the continuation or extent of their service due to lack of legislative protection. In August 2012, the Government of Ireland²³, without warning, announced that it was going to cancel the personal assistance budget for the rest of that year, which led to protests and the decision was eventually reversed. In August 2015, over 1,000 disabled people under the age of 65 were living inappropriately in nursing homes for older people.²⁴ In 2016, there were over 1,600 disabled people remaining on waiting lists for a personal assistance (PA) service throughout Ireland²⁵. In 2017, 84 percent of those in receipt of a PA service received less than three hours a day and 42 percent of these people were in receipt of between one and five hours a week. This is only an average of 42 minutes a day, despite there being 1,440 minutes in a day and disability being a 24-hour affair.²⁶ As far back as 1996, it was identified that an average need for 10 hours of PA service per person per week could only respond to essential personal care needs, not quality of life requirements²⁷ and it would certainly not enable full participation in the community.

²² MS Ireland, 'Home Care and Personal Assistance Services – Briefing Document and Position Paper' (MS Ireland October 2016) 3 <<https://www.ms-society.ie/blog-articles/2079-home-care-and-personal-assistance-services>> (accessed 04 December 2018).

²³ Center for Independent Living, 'Center for Independent Living Leader Forum Consultation Report: Personal Assistance Services.' (2016) 8 <<https://ilmi.ie/wp-content/uploads/2018/07/Personal-Assistance-Report-2016-.pdf>> accessed 14 January 2019

²⁴ Disability Federation of Ireland 'Press Release: Launch of the National Disability Inclusion Strategy 2017 - 2021' (Disability Federation of Ireland July 2017) <<https://www.disability-federation.ie/news/press-releases/2017/07/16/launch-of-the-national-disability-inclusion-strate/>> accessed 20 November 2018.

²⁵ Center for Independent Living, 'Center for Independent Living Leader Forum Consultation Report: Personal Assistance Services.' (2016) 29 <<https://ilmi.ie/wp-content/uploads/2018/07/Personal-Assistance-Report-2016-.pdf>> accessed 14 January 2019

²⁶ Aisling Glynn, 'My 'choice': 42 minutes help a day at home or 24 hours a day in residential care' The Irish Times (Dublin, 20 November 2018)

²⁷ Irish Wheelchair Association, Personal Assistance Services, <<https://www.iwa.ie/information/iwa-articles/youth-articles/club-cafe-news/item/personal-assistance-services>> accessed 27 November 2018

International Case Study: Sweden

Background

Adolf Ratzka is credited with bringing the concept of personal assistance to Sweden and with coining the terms 'personal assistance' and 'personal assistant'. In 1987 he persuaded local authorities in Stockholm to let him run a pilot project.²⁸ The following year, a Parliamentary Committee confirmed that the home care services and cluster housing services for disabled people were of inferior quality.²⁹ In 1994, following strong political support and pressure from the Independent Living movement, the 'Act concerning Support and Service for Persons with Certain Functional Impairments (LSS Act - a Swedish acronym) introduced the individual right to a personal assistance service for those eligible, or funding to enable purchase of such assistance, which the individual has to apply for³⁰. It was not primarily a right to self-determination for disabled people, but more as a necessary political remedy to the miserable conditions experienced by disabled people within the municipal home help services of the time.³¹

Sweden has long been regarded as the ground-breaking country and 'gold standard' for personal assistance. It remains the only European country which legally confers a right to personal assistance, although there is some legislation in this area in many countries, such as Denmark, France, Germany, Latvia, Norway, Serbia, Slovakia, Spain and the UK³².

'We might suggest that Sweden is offering its disabled citizens full choice and control over the support they need to live independently,

²⁸ Bengt Westerberg, 'Personal Assistance - A Revolution For People With Disabilities – Keynote' (7th International Conference on Social Work in Health and Mental Health, University of Southern California, June 2013) <<https://www.independentliving.org/docs6/Westerberg-Swedish-disability-policy.html>> accessed 28 November 2018

²⁹ Kenneth Westberg, 'Personal Assistance in Sweden' (Independent Living Institute, July 2010) 12 <https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> accessed 02 November 2018

³⁰ Örnköldsviks kommun, 'Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)' <<http://www.ornskoldsvik.se/download/18.44a4cd7915743e6a7e926737/1475832232342/Om%20LS%20p%C3%A5%20Engelska.pdf>> accessed 06 December 2018

³¹ Susanne Berg, 'Personal Assistance Reforms in Sweden: breaking the assumption of dependency?' in Colin Barnes and Geof Mercer (eds) *The Social Model of Disability: Europe and the Majority World* (Leeds: The Disability Press 2005) 44

³² European Network on Independent Living, 'Personal Assistance Services in Europe', (*Enil.eu*, 2013) 26 <<https://enil.eu/wp-content/uploads/2013/02/European-Survey-on-Personal-Assistance-Final.pdf>> accessed 06 November 2018.

with (almost) equal access to the same mainstream services as other non-disabled citizens.³³

Eligibility

Support and service under the LSS Act is open to both children and adults “who: have intellectual disabilities or autism, or who have a condition resembling autism; have considerable and permanent mental impairment following brain damage sustained as an adult, as a result of external force or physical illness; have some other lasting physical or mental impairment that is clearly not due to normal aging, ...”³⁴ and who need assistance in at least one of the activities of daily living, such as help to dress / undress, personal hygiene, eating, communication, or other assistance from someone with detailed knowledge of their specific functional impairment.

In 2015, 69,500 people were granted services under the LSS Act, 40 percent were women and 60 percent were men³⁵. They are entitled to ten services³⁶, including personal assistance; companion service (for those without personal assistance); contact person (to provide support and reduce isolation); relief service in the home; short stay away from home.³⁷ For each of these services, an individual assessment of need is required³⁸.

³³ Ruth Townsley et al., ‘The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report’ (Academic Network of European Disability experts, January 2010) 3 <<https://www.disability-europe.net/downloads/284-aned-task-5-independent-living-synthesis-report-14-01-10>> accessed 26 November 2018

³⁴ Örnköldsviks kommun, ‘Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)’ <<http://www.ornskoldsvik.se/download/18.44a4cd7915743e6a7e926737/1475832232342/Om%20LS%20p%C3%A5%20Engelska.pdf>> accessed 06 December 2018

³⁵ Government Offices of Sweden, Information on services available for persons with disabilities in Sweden <<https://www.ohchr.org/Documents/Issues/Disability/ProvisionSupport/States/Permanent%20Mission%20of%20Sweden.docx>> accessed 17 December 2018

³⁶ Örnköldsviks kommun, ‘Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)’ <<http://www.ornskoldsvik.se/download/18.44a4cd7915743e6a7e926737/1475832232342/Om%20LS%20p%C3%A5%20Engelska.pdf>> accessed 06 December 2018

³⁷ *ibid.*

³⁸ Government Offices of Sweden, Information on services available for persons with disabilities in Sweden <<https://www.ohchr.org/Documents/Issues/Disability/ProvisionSupport/States/Permanent%20Mission%20of%20Sweden.docx>> accessed 17 December 2018

Assessment

To apply, the applicant obtains a doctor's statement describing the disability and how it affects them³⁹ and then fills in an application form. Both are then sent to the applicant's local municipality, if under 20 hours per week assistance is required⁴⁰, or sent to the National Social Insurance Office (Försäkringskassan) if over 20 hours per week of assistance is required⁴¹. The investigation process begins by officials evaluating if the applicant meets the criteria for the LSS Act, and if the person's condition is chronic, resulting in extensive needs requiring support in everyday life.⁴² Then an assessment is conducted through open ended interviews, during a home visit or in the assessing official's office, with the disabled person describing all regularly occurring aspects of everyday life, those they need help with, and how long they take.⁴³ An occupational therapist or a physiotherapist may be consulted, if required.⁴⁴ The assessment is carried out by officials from the Social Service Office of the local municipality, and / or officials from the National Social Insurance Office (Försäkringskassan). The latter also assess the right to assistance with other daily life activities, such as shopping and leisure-time activities⁴⁵. Daily life here is defined as 'expected, continuous, daily or frequent activities or everyday situations.'⁴⁶ The assistance is reviewed every two years to ensure any changing needs are met⁴⁷ and

³⁹ *Försäkringskassan*, 'Attendance Allowance for An Adult' <https://www.forsakringskassan.se/privatpers/funktionsnedsattning!/ut/p/z1/04_Sj9CPykssy0xPLMnMz0vMAfljo8ziTTxcnA3dnQ28DVxNHQ0cXb3DXD38fQxNPM30w8EKDHAARwP9KEL6o1CVWLgbmxo4BgYYGpv4G3l5BRtAFcXljg1T78gN8lgy8RREQDenCRp/?1dmy&urile=wcm%3apath%3a%2Fcontentse_responsive%2Fprivatpers%2Ffunktionsnedsattning%2Fassistanstersattning> accessed 09 December 2018

⁴⁰ Socialstyrelsen 'Swedish disability policy – service and care for people with functional impairments', (2009-126-188) 9 <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf> accessed 11 December 2018

⁴¹ *Försäkringskassan*, 'Attendance Allowance for An Adult' <https://www.forsakringskassan.se/privatpers/funktionsnedsattning!/ut/p/z1/04_Sj9CPykssy0xPLMnMz0vMAfljo8ziTTxcnA3dnQ28DVxNHQ0cXb3DXD38fQxNPM30w8EKDHAARwP9KEL6o1CVWLgbmxo4BgYYGpv4G3l5BRtAFcXljg1T78gN8lgy8RREQDenCRp/?1dmy&urile=wcm%3apath%3a%2Fcontentse_responsive%2Fprivatpers%2Ffunktionsnedsattning%2Fassistanstersattning> accessed 09 December 2018

⁴² Kerstin Gynnerstedt, Hans Bengtsson, 'Personal assistance in Sweden – Support and service for persons with certain functional impairments (2011) 23(1-2) Aotearoa New Zealand Social Work 18, 21 <<https://anzswjournal.nz/anzsw/article/view/166>> accessed 15 December 2018

⁴³ *ibid* 22

⁴⁴ *ibid*

⁴⁵ Ulla Clevnert and Lennarth Johansson, 'Personal Assistance in Sweden, Journal of Aging and Social Policy' (2007) 19(3) Journal of Aging and Social Policy 65, 70

⁴⁶ Kerstin Gynnerstedt, Hans Bengtsson, 'Personal assistance in Sweden – Support and service for persons with certain functional impairments (2011) 23(1-2) Aotearoa New Zealand Social Work 18, 22 <<https://anzswjournal.nz/anzsw/article/view/166>> accessed 15 December 2018

⁴⁷ Kenneth Westberg, 'Personal Assistance in Sweden' (Independent Living Institute, July 2010) 12 <https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> accessed 02 November 2018

there is the possibility of appealing negative decisions in writing to an administrative court of appeal, in the first hand, the County Administrative Court⁴⁸. A combination of medical, social and psychological factors is the base for this assessment.⁴⁹ Many cases and situations are problematic to assess.⁵⁰ Difficulties occur when assessing longevity with conditions that are not yet stable, and complex disabilities, such as psychiatric diagnosis, and those with poor prognosis, also prove challenging.⁵¹ The competence, experience and continuity of staff carrying out the assessment can also prove difficult.⁵²

Hours

The assessment of need is primarily based upon the person's actual requirement of hours of assistance per week, not activities or levels of impairment. There are no upper limits, as a 24 hour a day / seven day a week service is a feature of the system, with the possibility of receiving double assistance, if required. Additional hours can be granted for temporary illness, holidays or tasks at work that require more assistance. On average the personal assistance received is for approximately 115 of the week's 168 hours. Some beneficiaries have two assistants simultaneously, at times, contributing to the high average⁵³. The need for personal assistance in all activities concerned with daily life is considered, based on lifestyle.

Funding

The budgets for personal assistance are determined, regardless of the personal income of the budget holder. If less than 20 hours per week is required, the local

⁴⁸ Socialstyrelsen 'Swedish disability policy – service and care for people with functional impairments', (2009-126-188) 9 <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf> accessed 11 December 2018

⁴⁹ Kerstin Gynnerstedt, Hans Bengtsson, 'Personal assistance in Sweden – Support and service for persons with certain functional impairments (2011) 23(1-2) Aotearoa New Zealand Social Work 18, 21 <<https://anzswjournal.nz/anzsw/article/view/166>> accessed 15 December 2018

⁵⁰ *ibid.*

⁵¹ *ibid.*

⁵² Government Offices of Sweden, Information on services available for persons with disabilities in Sweden <<https://www.ohchr.org/Documents/Issues/Disability/ProvisionSupport/States/Permanent%20Mission%20of%20Sweden.docx>> accessed 17 December 2018

⁵³ Bengt Westerberg, 'Personal Assistance - A Revolution For People With Disabilities – Keynote' (7th International Conference on Social Work in Health and Mental Health, University of Southern California, June 2013) <<https://www.independentliving.org/docs6/Westerberg-Swedish-disability-policy.html>> accessed 28 November 2018

municipality funds this budget⁵⁴. Once the assistance required is over 20 hours per week, there is one centralised source of funding, which is the National Social Insurance Fund (state money)⁵⁵. This is through the entitlement of an 'Assistance Benefit', as identified in the 'Act concerning Compensation for Assistance' (LASS - a Swedish acronym).⁵⁶

Flexibility

The disabled person has flexibility, both over the hours within a six-month period and how the budget is spent.⁵⁷ They can choose between the municipality, a company, a cooperative or a private company can be started for the administration of the service.⁵⁸ Funds are paid in advance and assistance users can also apply for payment of accompanying assistants event entrance tickets, meals, accommodation and transportation.⁵⁹ The support is 'coordinated and tailored to suit the user's individual needs and designed so that it is accessible to those who need it, strengthening the ability to live an independent life'.⁶⁰ Notably it has created a demand-driven market for personal assistance, where providers compete for customers based on service quality.⁶¹ Ninety-eight percent of disabled people said personal assistance was the most important factor for their quality of life.⁶²

'Service and support through a personal assistant has been described as the prime political tool for strengthening the participation and

⁵⁴ Sinéad Keogh and Gerard Quinn, 'Independent Living: An Evaluation of the Áiseanna Tacaíochta Model of Direct Payments' (2018) 11
<https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf> accessed 2 December 2018

⁵⁵ *ibid*, 10

⁵⁶ Örnköldsviks kommun, 'Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)'
<<http://www.ornskoldsvik.se/download/18.44a4cd7915743e6a7e926737/1475832232342/Om%20LS%20p%C3%A5%20Engelska.pdf>> accessed 06 December 2018

⁵⁷ Kenneth Westberg, 'Personal Assistance in Sweden' (Independent Living Institute, July 2010) 12
<https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> accessed 02 November 2018

⁵⁸ *ibid*, 30

⁵⁹ *ibid*, 8

⁶⁰ Heléne von Granitz et al. 'Do personal assistance activities promote participation for persons with disabilities in Sweden?' (2017) 39(24) *Disability and Rehabilitation* 2512, 2513

⁶¹ Zero Project, *Innovative Policy 2015 on Independent Living Sweden's Personal Assistance Budget*
<<https://zeroproject.org/policy/sweden-3/>> 11 December 2018

⁶² *ibid*

independence of persons with disabilities in Sweden by comprehensive rights and choices for the eligible.’⁶³

Development

Sweden is often looked up to by other countries looking for best practice in this area. Despite ratifying the UN CRPD in 2008, due to political pressure and increased costs State authorities seem to be changing the interpretation of the personal assistance legislation away from the human rights approach (that of the UN CRPD), to assessing individual needs for personal assistance services using a more medical approach. The assessment process changed from personal need interviews to an excessive reliance on scientific assessment tools where only active time, calculated by the minute, was counted.⁶⁴ Due to the narrowing of the eligibility criteria, there has been a sharp increase in rejected applications and people losing state funded personal assistance.⁶⁵ Also, only 3% of users employ their own personal assistants directly and this has remained constant over time, as most users seem unwilling to take the responsibility or burden of becoming an employer.⁶⁶

Arguments For

Single-issue Legislation

New stand-alone personal assistance legislation could prove relatively straightforward in getting passed through the Oireachtas. In the last couple of years, similar successful examples of Private Members’ Bills were the Irish Sign Language Act 2017⁶⁷ and the Mental Health Amendment Act 2018⁶⁸. Both of these Acts took less than a year and a half from initiation to being signed into law which demonstrates that it is possible to get bills through quickly if necessary. However, it should be noted that neither have been commenced and therefore are not legally in force.

⁶³ Heléne von Granitz et al. ‘Do personal assistance activities promote participation for persons with disabilities in Sweden?’ (2017) 39(24) Disability and Rehabilitation 2512, 2513

⁶⁴ Kenneth Westberg, ‘Personal Assistance in Sweden’ (Independent Living Institute, July 2010) 12 <https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> accessed 02 November 2018

⁶⁵ Ciara Brennan, et al. ‘Are Cutbacks to Personal Assistance Violating Sweden’s Obligations under the UN Convention on the Rights of Persons with Disabilities?’ (2016) 5(2) Laws 23

⁶⁶ Kenneth Westberg, ‘Personal Assistance in Sweden’ (Independent Living Institute, July 2010) 12 <https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> accessed 02 November 2018

⁶⁷ Irish Sign Language Act 2017

⁶⁸ Mental Health (Amendment) Act 2018

Social Model of Disability

New legislation could ensure that the rights-based social model of disability is used widely, as promoted by the ILMI ⁶⁹, not the charity / medical model which is currently prevalent. It could ensure that there is no discrimination based on the type of perceived level of disability and all types of disability – physical, sensory, intellectual and psychosocial disabilities, could receive personal assistance, if required. It could also ensure that there are no age discrimination or restrictions on the eligibility for PA services.

Flexibility

New legislation could set out exactly how the personal assistance would be funded and managed, with the individual given the right to recruit, train, manage and evaluate the assistance⁷⁰, and ensure PA remuneration is in line with current rates of pay. It would also ensure flexibility and customisation of services, according to individual needs with maximum control over everyday life.

UNCRPD Duties

As Ireland recently ratified the UNCRPD, the implementation of new personal assistance legislation, would illustrate that Ireland is taking its duties under the UNCRPD seriously and enable it to move forward with its commitments for equal rights and equal treatment of disabled people. It would also promote a positive international image of Ireland, as a progressive country with regards to disabled people and facilitate the exchange of ideas and knowledge about good practice with other countries worldwide.

Arguments Against

Confusion with other services

It may also conflate personal assistance with home help which are two distinct areas of support. For example, in Sweden, a legal reform enacted in January 2001, extended the right to retain personal assistance after becoming 65, although limited to the

⁶⁹ Independent Living Movement Ireland, 'Vision, Mission and Values' <<https://ilmi.ie/our-vision-mission-and-values/>> accessed 17 December 2018

⁷⁰ European Network on Independent Living, 'Personal Assistance Services in Europe 2015' <<https://www.enil.eu/wp-content/uploads/2012/06/Personal-Assistance-Service-in-Europe-Report-2015.pdf>> accessed 6 November 2018

number of hours received before the 65th birthday. If more hours are needed after 65, these can be provided under the Social Care Act (home care).⁷¹

Substantial Support Required

The legislation would need considerable political and public support and go through a potentially lengthy time-consuming process to be enacted and commenced. If it did not receive enough support, as it may be perceived to benefit only a minority group, it may result in not making the existing system better for disabled people.

Time-consuming

The required legislation would need to be very comprehensive, detailed and prescriptive to be effective. It would need comprehensive input from all stakeholders and clear guidance on the commissioning strategy and this would all take considerable time and effort.

Mirror existing policy

It is also possible that any legislation may follow the provisions that exist at present for personal assistance, which means that the medical model may be used, and all types of disabilities and all ages may not be treated equally.

⁷¹ Kenneth Westberg, 'Personal Assistance in Sweden' (Independent Living Institute, July 2010) 12 <https://www.independentliving.org/files/Personal_Assistance_in_Sweden_KW_2010.pdf> accessed 02 November 2018

Option Two: A Comprehensive Right to Community Care and Support

Background

In Ireland, as in many jurisdictions around the world, personal assistance is provided through systems of health and social care – as part of a social commitment to community care. This section will consider whether a right to personal assistance should be recognised as part of a broader recognition of a right to community care for disabled people and older people – particularly in light of a growing consensus in Ireland that disabled people and older people should be entitled to support to remain in their own homes, and in their own communities, for as long as possible. Personal assistance is one important form of support that can facilitate people remaining in, or moving into, their own homes, and remaining part of their communities, rather than entering institutional or long term residential (or congregated) care.

International Case Study: England

The Care Act 2014, which came into force in April 2015, governs the assessment of needs and eligibility for access to social care services in England.⁷² Under the Act local authorities must assess anyone who requires care or support regardless of their likely eligibility for state-funded care. In contrast to other legislation which confer an entitlement on the individual the Care Act places a duty on local authorities.

The Care Act is typically referred to regarding the use of direct payments to access personal assistance, as outlined below. However, disabled people who are eligible for direct payments under the Act but who choose not to avail of this option can also have a personal assistant provided to them by a local authority or service provider.

Eligibility

There are three conditions to determine eligibility for care and support under the Care Act 2014.

⁷² The Academic Network of European Disability Experts (ANED), 'UK – Independent Living' <https://www.disability-europe.net/dotcom/?l%5B%5D=33&t%5B%5D=23&t%5B%5D=24&t%5B%5D=25&t%5B%5D=26&t%5B%5D=27&t%5B%5D=28&t%5B%5D=29&t%5B%5D=30&view_type=list> accessed 5 February 2019

1. If the adult has "a physical or mental impairment or illness" which is not circumstantial including conditions as a result of a physical, mental, sensory or cognitive disability or illness and substance misuse and brain injury.
2. and that as a result of the adult's needs, they are unable to achieve two or more of the outcomes specified in the Act's regulations without support,
3. and as a result of not being able to achieve the outcomes, the adult's wellbeing is significantly impacted.⁷³

The Care Act differs from previous legislation in England as it places an obligation on local authorities to focus on the person's needs, how they impact their wellbeing, and the outcomes they want to achieve during an assessment.⁷⁴ The concept of wellbeing under the Act is very broad. Under this obligation the local authority the individual's opportunities to "control day-to-day life (including over care and support provided and the way it is provided", participate "in work, training, or recreation", contribute to society and their "domestic, family or personal" wellbeing.

Assessment

Beyond a duty to assess an individual, local authorities must also "involve the person in the assessment and, where appropriate, their carer or someone else they nominate".⁷⁵ They must also "provide access to an independent advocate to support the person's involvement in the assessment if required."⁷⁶

Assessments, which can be completed in various formats including face to face assessments or online assessments, are carried out by professionals with the relevant training and appropriate skills including social workers, and occupational therapists (OT's).⁷⁷ There is also the option to complete a Supported Self-Assessment

⁷³ Social Care Institute for Excellence, Eligibility criteria for adults with care and support needs under the Care Act 2014, <<https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/criteria-adults-care.asp>> accessed 5 February 2019

⁷⁴ Social Care Institute for Excellence, Care Act 2014, <<https://www.scie.org.uk/care-act-2014/>> accessed 5 February 2019

⁷⁵ *ibid*

⁷⁶ *ibid*

⁷⁷ Disability Rights UK, 'Your Guide to the Care Act: What you need to know about social care in England' (January 2017)

Questionnaire (SSAQ) however, an assessor will oversee the process to ensure the full range of needs are identified.

The assessor will ensure the individuals edibility and if they are unable to achieve two or more of the outcomes. When considering whether an individual is "unable to achieve" an outcome, as set out above, local authorities must take into account whether a person, while being able to achieve the outcome experiences difficulty with achieving it safely, that the person may need some support with prompts in order to do the task, and also if the person is not being caused significant pain, distress or anxiety when carrying out the task.

After an assessment an individual will be supported by the local authority to prepare a care and support plan which sets out how best to meet their needs. It is at this point that an individual or their supporters will choose whether to receive a direct payment, as outlined in the next section, or opt to have the local authority or service provider manage the funding.

Arguments For

Applicable to people of all ages

Currently disabled people in Ireland typically transfer from disability services, supports and entitlements at the age of 65 to older peoples services. For those in receipt of personal assistance this means a change from the 'leader model' of personal assistance to Home Support Service. Under a community care model there could be a guaranteed continuity of care and support for disabled individuals over the age of 65.

This could also be helpful from a lobbying perspective as support could be gained from older people and their representative organisations. Currently, arguments for a right to community care for older people (as an alternative to Fair Deal) are gaining political support. This approach would build solidarity between disabled people and older

people and ensure that a right to personal assistance does not end at 65 for disabled people.

Duty on Public Body

There is often a reluctance to create new rights to services or supports. Therefore, following the community care model in England could garner additional support and may be easier to progress through the Oireachtas as it places a duty on a public body instead of creating new entitlements. However it should be noted that unlike in England, local authorities in Ireland do not deliver community or social care services, so relevant public body in the Irish context would likely be the HSE, or at the local level, the various Community Health Organisations within the HSE.

Arguments Against

Does not create an explicit right

Adopting a community care model as seen in England places an onus on the local authority or its equivalent to assess needs but does not guarantee an express right to personal assistance.

Terminology

The terminology of ‘community care’ may not fit easily with the ethos of the independent living movement. The inclusion of personal assistance within a broader entitlement to community care may risk conflating the distinct concept of personal assistance (in which assistance must be directed and controlled by the individual receiving support) with other concepts like home help or home care.

Option Three: Legislation for Personalised Budgets

Background

As set out above a personal budget, or direct payment in the English context, is a ‘sum of money given to a person with a disability by a state authority to arrange and meet their care needs instead of having them met directly by the state’.⁷⁸ Personal assistance is often purchased using a personal budget however, the individual is not restricted to spending it solely on personal assistance. The budget can be used to cover other disability-related costs such as equipment, travel and technology, alongside the provision other services and supports to enable participation in the community and home care support. It must be noted that funds from a personalised budget cannot be used on general expenses, such as food and drink, bills or mortgage payments. They also cannot be used on services given by other Government Departments or agencies.

There is currently no legal right to a personal budget in Ireland. However, the Irish Government has announced its intention to re-allocate a proportion of public spending from the traditional disability service model, to one based on personal budget with the goal of enabling citizens to acquire services better suited to their needs.

Several policy documents in Ireland, such as the ‘Value for Money and Policy Review of Disability Services in Ireland’ (VFM Review)⁷⁹, the ‘Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments’ (Independent Living Report)⁸⁰ and the ‘Towards Personalised Budgets for People with A Disability in Ireland Report of The Task Force on Personalised Budgets’ (Task Force Report)⁸¹ recognise extensive social and monetary benefits for service users availing of personalised budgets. In directing their own service, individuals are given more

⁷⁹ Department of Health, Value for Money (VFM) and Policy Review of Disability Services in Ireland (July 2012) <https://health.gov.ie/wpcontent/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf> accessed 11 January 2019

⁸⁰ Sinéad Keogh and Gerard Quinn, 'Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments' (2018) <https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf> accessed 2 December 2018

⁸¹ Department of Health, Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets (June 2018) <<https://health.gov.ie/wp-content/uploads/2018/07/Task-Force-Report.pdf>> accessed 14 January 2019

control, independence and choice over meeting their support needs. There is also a wider choice of equipment, personal assistants and other facilities necessary to meet one's needs. The Independent Living Report found cost-efficiencies of €66,162 were made from eighteen leaders directing personal assistance alone through the AT Model of Direct Payments⁸².

International Case Study: England

Direct payments have existed in England for over two decades and are the English Government's preferred mechanism for personalised care and support⁸³. They were first introduced for working age adults in England under the Community Care Act 1994, which was implemented in 1997. Eligibility was later extended to parents of disabled children, older persons and people appointed to receive direct payments on behalf of others who may lack mental capacity. The provision of direct payments is now a duty of local authorities. Prior to the enactment of legislative provisions recognising direct payments, authorities had the power to issue direct payments, but they were under no obligation to do so. Around 500,000 adults in England received direct payments between 2014 and 2015.⁸⁴ Within this time-frame, local authorities spent £1.37 billion on direct payments for users and £42 million on direct payments for carers.⁸⁵

Clinical Commissioning Groups (CCGs) are bodies established by the NHS responsible for planning and commissioning health care services within their designated area.⁸⁶ The establishment of a care plan is the result of a care planning discussion between Clinical Commissioning Groups and the receiver of the direct payment, or a representative. It sets out the healthcare and wellbeing needs that are

⁸² Sinéad Keogh and Gerard Quinn, 'Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments' (2018)

<https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf> accessed 2 December 2018

⁸³ Department of Health and Social Care, 'Care and Support Statutory Guidance' (2018) 12.2

<<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>> accessed 5 December 2018

⁸⁴ Comptroller and Auditor General, 'Department of Health and Local Authorities: Personalised Commissioning in Adult Social Care' (National Audit Office 2016) 7 <<https://www.nao.org.uk/wp-content/uploads/2016/03/Personalised-commissioning-in-adult-social-care-update.pdf>> accessed 4 December 2018

⁸⁵ *ibid* 29

⁸⁶ NHS Clinical Commissioners, 'About CCGs'. <<https://www.nhscc.org/ccgs/>> accessed 17 January 2019

to be addressed.⁸⁷ The care plan is not direct payment specific, it lays out a broad range of support necessary to meet the care and wellbeing needs of the person and the level of financial support and personal assistance necessary to meet these needs.

Employing personal assistants carries the legal, financial and practical responsibilities attached to the role of employer. While added responsibility can act as a disincentive to some individuals, there are facilities available that provide protection to those concerned such as the personal assistants register. This enables employers to search for personal assistants based on geographical location, skill level, experience and availability.⁸⁸ The 'employing personal assistants tool kit' also guides employers through the process of employing personal assistants.⁸⁹

There is no standardised method of calculating a direct payment. Many local authorities use a Resource Allocation System (RAS), which is a system based on statistical information about care costs used to calculate the amount needed to meet the needs of individual.⁹⁰ The RAS produces an indicative figure, which is an estimated cost attached to purchasing care and support to meet someone's needs. The indicative figure is used as the focal point for the care planning discussion. The standards of transparency, timeliness and sufficiency are enforced throughout the process.⁹¹

Direct payments are reviewed after six months, and annually after that. The frequency of review may fluctuate depending on the capacity and health condition of the individual. The purpose of the review is to ensure the individual is managing the direct

⁸⁷ NHS England Patient Participation Team, 'Guidance on Direct Payments for Healthcare: Understanding the Regulations' (NHS 2014) 24 <<https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf>> accessed 05 February 2019

⁸⁸ College of Social Work and the National Skills Academy, 'Direct Payments Workbook' (*Skillsforcare.org.uk*, 2018) 31 <<https://www.skillsforcare.org.uk/Document-library/Standards/Care-Act/learning-and-development/person-centred-care-and-support-planning/direct-payments-workbook.docx>> accessed 1 December 2018.

⁸⁹ Skills for Care, 'Employing Personal Assistants Toolkit' <<https://www.employingpersonalassistants.co.uk/>> accessed 8 December 2018.

⁹⁰ Age UK, 'Factsheet 24: Personal Budgets and Direct Payments in Social Care' (December 2018) 6 <https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs24_personal_budgets_and_direct_payments_in_social_care_fcs.pdf> accessed 05 February 2019

⁹¹ Think Local Act Personal, 'Developing A Resource Allocation System (RAS): Accuracy and Transparency at The Heart of The Indicative Budget'. <https://www.thinklocalactpersonal.org.uk/assets/Resources/TLAP/MPF/Derby_RAS_Case_study_-_assessment_-_Resource_allocation_revised.docx> accessed 3 December 2018

payment correctly, that direct payments are sufficient to cover needs and that the receiver is complying with conditions attached to the agreement. If the individual is employing people, these include maintaining adequate employment conditions, ensuring national insurance contributions and employment tax are all in order.⁹² It also provides the individual with an opportunity to voice any concerns or queries they may have.

Direct payments are commonly used to employ personal assistants in England, however they are not the only way to access personal assistance in England. Section 1 (2) (d) of the Care Act 2014 places a legal duty on local authorities to provide or arrange services that promote independence for people with disability.⁹³ Local authorities can directly commission personal assistance if the person is unable or unwilling to access personal assistance using the direct payment scheme. While those who have their personal assistance commissioned directly will not enjoy the choice, control and freedom of directing one's own care provision, they will also not carry the administrative burden attached to doing so.

Arguments For

Scope

A major benefit to organising one's own personal assistance using personal budgets is that while a budget can be used on personal assistance, it is not restricted to that use. Personal budgets can be used in covering other disability-related costs. On a practical level, this aligns with the aims of ILMI as it provides the support necessary to enable disabled persons to live empowered independent lives.⁹⁴ Direct payment holders in England enjoy wide freedom in meeting their assistance needs. Alongside meeting their healthcare needs, direct payments can be used to purchase supports to socialise, participate in the community and to work. They can also be used to meet a wide range of disability-related costs such as purchasing equipment and travel.

Available across all disabilities

⁹³ Care Act 2014, s1(2)(d)

⁹⁴ Independent Living Movement Ireland, 'Strategic Plan 2019 - 2022' (2018) <<https://ilmi.ie/>> accessed 16 December 2018

As per the Task Force Report, all disabled adults will be considered for personal budgets, encompassing those with physical and sensory disabilities, and mental impairments and psychosocial disabilities.⁹⁵ While initially only being available to working age adults in England, direct payments have since been extended to parents of disabled children and older people.

Policy commitment

Minister Finian McGrath committed to implementing the recommendations made by the Task Force on Personalised Budgets report published in October 2018.⁹⁶ The Department of Health, National Disability Authority (NDA) and the HSE are currently designing the demonstration models.⁹⁷

Arguments Against

Age limitations

The Task Force Report recognises that half of countries have an upper limit of 65 and few have a lower age limit.⁹⁸ Similarly in Ireland once you turn 65 you lose most of your disability entitlements, which would suggest that Ireland would follow the half with the upper limit of 65. A recurring argument against individualised funding, is that it is disproportionately taken-up by younger persons with physical or sensory disabilities. This is reflected in direct payments, in 2014 - 2015 it was found that younger adults with physical disabilities were twice as likely to have a direct payments and older people were 40% less likely to use direct payments.⁹⁹

Administrative Burden

Directly employing a personal assistant carries all the legal, financial and practical responsibilities of being an employer. Budget holders are also expected to keep and

⁹⁵ Department of Health, Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets (June 2018) 1.2 <<https://health.gov.ie/wp-content/uploads/2018/07/Task-Force-Report.pdf>> accessed 14 January 2019

⁹⁶ Finian McGrath, 'Press Release: Minister McGrath Launches The Report Of The Task Force On Personalised Budgets' (2018) <<http://www.finianmcgrath.ie/minister-mcgrath-launches-the-report-of-the-task-force-on-personalised-budgets/>> accessed 15 December 2018

⁹⁷ Dáil deb 21 November 2018, Unrevised, col 181.

⁹⁸ Department of Health, Towards Personalised Budgets for People with a Disability in Ireland Report of the Task Force on Personalised Budgets (June 2018) 41 <<https://health.gov.ie/wp-content/uploads/2018/07/Task-Force-Report.pdf>> accessed 14 January 2019

⁹⁹ Comptroller and Auditor General, 'Department of Health and Local Authorities: Personalised Commissioning in Adult Social Care' (National Audit Office 2016) 34 <<https://www.nao.org.uk/wp-content/uploads/2016/03/Personalised-commissioning-in-adult-social-care-update.pdf>> accessed 4 December 2018

produce receipts and bank statements for review, to ensure they are spending within their budget. Coupled with the responsibility of organising your own care provision, the workload can act as a disincentive. Some authorities use services such as PayPal to reduce the financial review burden, giving them ready access to financial information. As many users often spend outside of their agreed plan, these systems provide necessary oversight, while easing the workload attached to direct payments.

Accessibility

The workload and responsibility attached to personal budgets can make them highly inaccessible to certain groups. Without the correct support circle or the support of a broker, it may be difficult for older persons or persons with intellectual disabilities and psychosocial disabilities to access direct payments. Individual service funding has proven to be an effective middle ground between the choice, control and responsibility of direct payments and the lack of choice and control of council managed services¹⁰⁰. Under this system, the budget holder chooses a provider to manage their budget. The provider then works with the individual to arrange their flexible support¹⁰¹. No specific tasks are pre-determined, the budget holder is empowered to plan with the provider who, what and where to spend the budget. This would be particularly useful for older people or those with high support needs.

Lack of portability between local authorities

An individual in England is free to move between local authorities. However, they cannot carry their direct payments benefits from one local authority to another. This places people in a position where they must start the process over and clear the bureaucratic hurdles attached to qualifying for direct payments, which is not a straightforward process. There is concern that this may be the case with personal budget users in Ireland. It is difficult to definitively say that will be the case as personal budgets are not yet available at a national level. However, the Independent Living Report indicates that people receiving other disability services consider their

¹⁰⁰Helen Sanderson, et al. 'Choice and Control for All: The Role of Individual Service Funds in Delivering Fully Personalised Care and Support' (Groundswell 2016).
<<http://www.helensandersonassociates.co.uk/wp-content/uploads/2015/04/Choice-and-Control-for-All-Groundswell-2012.pdf>> accessed 10 December 2018

¹⁰¹ Simon Duffy, 'Individual Service Funds and Contracting for Flexible Support' (Think Local Act Personal 2015) 4 <
<https://www.thinklocalactpersonal.org.uk/_assets/Resources/SDS/TLAPISFsContractingFINAL.pdf> accessed 8 December 2018

movement from one Community Healthcare Organisation (CHO) to another as restricted, due to the bureaucratic hurdles attached to their care provision.¹⁰²

Lack of underpinning legislation

Direct payments in England are underpinned by the Care Act 2014, which provides for the right to a direct payment. There is no legislation currently in place to underpin personal budgets in Ireland, nor is legislative implementation recommended by the Task Force. As it stands, there is no legislative right to a personal budget within the Irish system.

¹⁰² Sinéad Keogh and Gerard Quinn, 'Independent Living: An Evaluation of The Áiseanna Tacaíochta Model of Direct Payments' (2018) 6
<https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/Independent-Living_An-Evaluation-of-the-A%CC%81iseanna-Tacai%CC%81ochta-model-of-Direct-Payments.pdf> accessed 2 December 2018

Option Four: Commencement of the Disability Act 2005

Background

The Disability Act 2005 was enacted on the 8th July 2005 following lengthy and wide spread campaigns from disabled people, parents, and human rights advocates for the introduction of rights-based legislation in relation to disability.¹⁰³ To ensure the equal participation of disabled people in society, the Act supports the provision of disability-specific services and sets out to improve access to mainstream public services in the country. Key features of the Act include:

- provisions for an independent assessment of individual need for all disabled people
- ensuring the accessibility of public buildings and services provided by public bodies.

The Act has been criticised for falling short of the rights based approach.¹⁰⁴ It does not guarantee specific rights – an issue which alongside the lack of commencement of key provisions has left disabled people in Ireland dissatisfied.¹⁰⁵

This section will consider how personal assistance could be achieved through the full commencement of the Act. As the Act has not been fully commenced, many provisions do not have legal effect. For example, Part 2 of the Act is only partially commenced and therefore only children born after 1st June, 2002 are entitled to apply for an assessment of need under the Act.

International Case Study: France

One of the key pieces of legislation regarding independent living and the rights of disabled people in France is the 2005 - 102 Act entitled “Equal rights and opportunities, participation and citizenship of disabled persons”.¹⁰⁶ As with most countries France has a long and complex history regarding the development of

¹⁰³ Inclusion Ireland, ‘Submission to the Oireachtas Joint Committee on Justice, Defence and Equality on the operation of the Disability Act 2005’ 2

<<http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1110/submission-oireachtas-joint-committee-justice-2.pdf>> accessed 05 February 2019

¹⁰⁴ *ibid*

¹⁰⁵ Jurgen De Wispelaere and Judy Walsh ‘Disability Rights in Ireland: Chronicle of a Missed Opportunity’ (2007) 22(4) Irish Political Studies 517

¹⁰⁶ Act No. 2005-102 of 11 February 2005

disability law and policy.¹⁰⁷ This particular piece of legislation amended and replaced legislation from 1975 which centred on the individual's impairment.¹⁰⁸

The 2005 Act is based on the principles of accessibility and compensation. Under the Act, disability is defined as any activity limitation or any restriction to participation in life in society to which a person is subjected in his or her environment due to a substantial, durable or definitive alteration to one or more physical, sensorial, mental, cognitive or psychological functions, or to a polydisability or to a disabling problem of health.¹⁰⁹ The Act created a new payment to refund the cost of disability called *prestation de compensation du handicap* (PCH) or Disability Compensation Allowance. One of the primary functions of this allowance is to contribute to the cost of human assistance or PA services. Human assistance can be either through the direct employment of a personal assistant, through a service provider or a family carer.

Eligibility

Disabled people, under the age of 75 years and who acquired their disability before they were 60 years of age, are eligible for PCH under the Act.¹¹⁰ The payment is part of the social protection structure and does not require contributions to social insurance schemes¹¹¹ and is not means tested.¹¹² Therefore, PCH can also be paid to disabled children and teenagers¹¹³ and the payment is available to people in a range of situations including; at home, at work, in education and training.¹¹⁴ Disabled people living in France, who are not French citizens, but who hold a residence permit (not mandatory for EU and EFTA members) also qualify for this benefit.¹¹⁵

¹⁰⁷ Myriam Winance, Isabelle Ville, and Jean-François Ravaud, 'Disability Policies in France: Changes and Tensions between the Category-based, Universalist and Personalized Approaches' (2007) 9(3) *Scandinavian Journal of Disability Research* 160

¹⁰⁸ *ibid*

¹⁰⁹ Art. L. 114 Law of 11 February 2005

¹¹⁰ Article L114-1-1 Law of 11 February 2005.

¹¹¹ Catherine Barral et al, 'ANED country report on the implementation of policies supporting independent living for disabled people' (2009) < <https://www.disability-europe.net/downloads/268-aned-independent-living-report-france> > accessed 05 February 2019.

¹¹² Anne Revillard, 'Vulnerable Rights: The Incomplete Realization of Disability Social Rights in France' (2018) 7 *Social Sciences* 88

¹¹³ Disabled children and teenagers can receive PCH if they are also in receipt of Disabled Child Education Allowance (Allocation d'éducation pour enfant handicapé/ AEEH). For more information see <<https://ec.europa.eu/social/main.jsp?catId=1110&langId=en&intPageId=4536>> accessed 10 January 2019

¹¹⁴ Catherine Barral et al, 'ANED country report on the implementation of policies supporting independent living for disabled people' (2009) 20 < <https://www.disability-europe.net/downloads/268-aned-independent-living-report-france> > accessed 05 February 2019.

¹¹⁵ *ibid* 17

Assessment

Applications for PCH should be made to the state body MDPH (Maison Départementale des Personnes Handicapées). The MDPH, created by the 2005 Act, regroups the different entities dedicated to disability that existed previously and is essentially a one-stop shop per département¹¹⁶ with responsibility for all disability-related requests including benefit decisions.

The assessment for PCH takes into account both the gravity of the individual's impairment and the level of difficulty they encounter in performing the essential activities of daily life¹¹⁷. To be eligible an individual must be unable to perform one activity of daily life or have serious difficulty in undertaking at least two out of 19 activities which are divided into four areas: "Mobility; Self-care; Communication; General tasks and demands and Interpersonal interactions and relationships."¹¹⁸ The assessment is carried out by a multidisciplinary team from the local MDPH using a multidimensional assessment guide (GEVA / Guide d'évaluation multidimensionnelle) based on the WHO's International Classification of Functioning, disability and health.

Funding

Funding for the PCH is provided jointly by the regional governments known as départements (€590 million) and the new National Independent-Living Support Fund (Caisse Nationale de solidarité pour l'autonomie - CNSA) established by the Act (€500 million).¹¹⁹ To help disabled people manage their PCH budget, the Act requires the opening of Disability Centres to provide assistance.¹²⁰

The amount of compensation is dependent on individual assessment as well as considering the fixed national rates for each type of assistance and support.¹²¹

Funding rates will also vary based on the on the type of assistant chosen by the disabled person. For example, those directly employing a PA will receive up to €11.57 per hour; while those wishing to compensate a family member for their support or assistance will only receive €3.36 per hour (50% of guaranteed minimum wage) or

¹¹⁶ *Département* refer to administrative territory divisions lower than regions.

¹¹⁷ *ibid*

¹¹⁸ *ibid*

¹¹⁹ Ministère des Affaires étrangères, 'Policy for the disabled in France' (2007) 2.

¹²⁰ Article L114-1-1 Law of 11 February 2005.

¹²¹ *ibid*

€5.03 per hour (75% of guaranteed minimum wage if the family member has to give up other paid work).¹²²

Arguments For

Time

As the Disability Act 2005 is already enacted it would be a short and simple process to commence the remaining provisions of the Act in full. If necessary it would also be quicker to enact amendments rather than drafting new stand-alone legislation regarding personal assistance.

Fulfilling Obligations under the CPRD

Incorporating the right to personal assistance in the Disability Act would act as a starting point for the implementation of Article 19 CRPD.

Arguments Against

No guaranteed right

This option does not establish a clear right to personal assistance – as the Act only provides a right to an independent assessment of need, and provision of the services is dependent on their availability. Therefore, while personal assistance could be included within an individual's service statement under the Act, there is no guarantee that the required hours to meet all the person's needs would be provided as a legal right.

No option to challenge or complain

While the Disability Act does provide for an appeals process if a person is not satisfied with the outcome of their needs assessment, this is an internal process within the Department of Health and does not give individuals a right to challenge denial of services, including personal assistance, in the court system.

¹²² Catherine Barral et al, 'ANED country report on the implementation of policies supporting independent living for disabled people' (2009) 18 < <https://www.disability-europe.net/downloads/268-aned-independent-living-report-france> > accessed 05 February 2019.

Not fully commenced

Although enacted in 2005 the Disability Act has never been fully commenced. This would suggest a lack of political will to commence the Act in full now and which could impact the level of engagement with further debates or amendments if required.

Summary and Recommendations

Having reviewed all four options for recognising a right to personal assistance in legislation in Ireland, the following section summarises the major advantages and disadvantages of each approach.

Option One: Stand-Alone Legislation on Personal Assistance

A specific entitlement to personal assistance for disabled people could be recognised in new stand-alone legislation.

Advantage: This option gives the greatest freedom and flexibility to establish a right to personal assistance that is comprehensive, covering all types of disabled people and all age groups of disabled people.

Disadvantage: Drafting stand-alone legislation is a time-consuming process and one which requires significant political will to achieve results. Pursuing this option may risk losing opportunities to build solidarity with other groups (such as older people) in the short term.

Recommendation: This option can be pursued as a short to medium term strategy (for example, to get a Private Members Bill tabled) to ensure a right to personal assistance receives political attention. However, it is unlikely to result in recognition of personal assistance as a legal right without political support from government.

Option Two: A Comprehensive Right to Community Care and Support

An entitlement to personal assistance could be recognised in new legislation establishing a comprehensive right to community care and support for all who need it (including disabled people and older people).

Advantage: Arguments for a right to community care for older people (as an alternative to Fair Deal) are gaining political support. This approach would build

solidarity between disabled people and older people and ensure that a right to personal assistance does not end at 65 for disabled people.

Disadvantage: The terminology of ‘community care’ may not fit easily with the ethos of the independent living movement. The inclusion of personal assistance within a broader entitlement to community care may risk conflating the distinct concept of personal assistance (in which assistance must be directed and controlled by the individual receiving support) with other concepts like home help or home care.

Recommendation: This option could be pursued as a medium to long term strategy if community care is defined as community support in a way which fits the ethos of the independent living movement. It would support efforts to build solidarity between disabled people and older people’s movements.

Option Three: Legislation for Personalised Budgets

An entitlement to personal assistance could be recognised in new legislation which is needed to underpin the recommendations of Minister McGrath’s Task Force on Personalised Budgets.

Advantage: There is clear political will from the Minister to introduce personalised budgets, so any legislation needed to do this (including legislation that recognises personal assistance as a relevant expense on which a personalised budget can be spent) would have political support.

Disadvantage: Some people will not want to use a personalised budget to access personal assistance. Managing personalised budgets can result in significant administrative and bureaucratic burdens. While steps can be taken to reduce the burden on individuals of managing their budgets, not everyone has access to the support they would need in order to do this and there is as of yet no clarity on how this support would be guaranteed by law.

Recommendation: This option could be pursued as a medium-term strategy for recognising a right to personal assistance if guarantees were in place to reduce

administrative complexity and bureaucratic burdens so as to make the task of managing a personal budget accessible to all.

Option Four: Commencement of Disability Act 2005

An entitlement to personal assistance could be recognised through the commencement of remaining provisions of the Disability Act 2005.

Advantage: This does not require further legislation to be passed, meaning it could happen quite quickly.

Disadvantage: This option does not establish a clear right to personal assistance – as the Act only provides a right to an independent assessment of needs. While personal assistance could be included within an individual’s service statement under the Act, there is no guarantee that the required hours to meet all the person’s needs would be provided as a legal right.


Recommendation: This option does not guarantee personal assistance as a right so it should not be pursued.

Overall Recommendation

From the research conducted for this report it seems that stand-alone legislation is the most straight-forward way to recognise the right to personal assistance for disabled people. However, the comparative research conducted for this report shows that there are many factors which need to be carefully considered in drafting such legislation. First, the eligibility for personal assistance must be determined. Decisions will have to be made as to whether to expand the current eligibility for personal assistance (currently only those aged 18 - 65 years can access this service). For example, new legislation could expand this right to children and young disabled people and / or to older persons (with or without disabilities).

The legislation will also have to set out how the amount of personal assistance an individual will receive will be determined. Comparative research has demonstrated that legislation which draws this entitlement too narrowly does not meet the requirements of international human rights law. Where legal rights to personal assistance are focused more on personal care than on facilitating the individual's participation in society (including in education and employment) then this does not fully meet the goals of the global independent living movement. Systems in which the level of personal assistance provided is based primarily on a medical assessment of impairment rather than a more comprehensive assessment of the individual's needs for support to participate in society are also problematic from a human rights standpoint. Similarly, any new legislation would have to clarify whether personal assistance is a right of all disabled people, including those with intellectual, psychosocial and cognitive disabilities – or whether it is confined to persons with physical and sensory impairments.

Finally, the legislation must clarify how funding for personal assistance will be accessed by individuals, and ensure that those who need or wish to use support in managing a personal assistance budget will not be unfairly disadvantaged by an overly bureaucratic and administratively burdensome system. If all these issues – eligibility, scope, access and use of personal assistance – are addressed in an inclusive and accessible manner, then the resulting legislation would be a major step forward in the recognition of the rights of disabled people in Ireland.



Nothing about us without us

Independent Living Movement Ireland

Carmichael House, North Brunswick Street, Dublin 7.

Tel: +353 (0)1 873 04 55 Email: info@ilmi.ie

www.ilmi.ie